
Colorado Newborn Screening Committee

June 28, 2016

4:00 – 6:00 PM

Meeting Minutes

Members present: Anne Behring, Mary Kohn, Michelle Miller, Suzanne Rogers, Joe Toney, Patrice Whistler, Lori Wise

Members absent: Kay Kelly, Teri Hulett

I. Ad Hoc Members Announced

The Committee's newly confirmed ad hoc content experts were announced. These individuals have gone through an application process, with their applications reviewed and approved by Committee members. More ad hoc members may be added in the future.

Ad Hoc Member	Specialty
Jordan Abbot	Pediatric Immunology
Peter Baker, MD	Biochemical Genetics
Jennifer Barker, MS	Pediatric Endocrinology
Dessie Berry	Parent of Deaf Child
Stephen Cass	Audiology
Stacy Claycomb	Audiology
Curtis Coughlin	Bioethics, Genetic Counselor
Aristides Maniatis	Pediatric Endocrinology
Stacey Martiniano	Pediatric Pulmonology
Chris Rausch	Pediatric Cardiology
Scott Sagel	Pediatric Pulmonology
Marci Sontag	Epidemiology
Carleigh Soule	Wyoming Newborn Screening Program
Janet Thomas	Biochemical Genetics

II. Newborn Screening Program Updates

Karen Trierweiler, Deputy Director of the Prevention Services Division, attended the meeting to update the Committee on some recent programmatic changes and the future direction of the newborn screening program. The Colorado Department of Public Health and Environment (the Department) has three newborn screening programs – newborn bloodspot screening, newborn hearing screening and critical congenital heart disease screening. Department leadership has a goal to integrate these three programs and maximize available staff and financial resources. Additional information will be available in the coming months.

III. Development of Committee Bylaws

The Committee continued to review the draft bylaws for the Committee, a process that began at the March meeting. Committee members moved through the draft bylaws section by section, making suggestions where they thought the document could be improved. Erica Wright, the Committee Administrator, made note of these suggestions and will incorporate them into the next draft of the bylaws.

IV. Newborn Screening of Refugee Infants

At the March meeting of the Committee, Dr. Janine Young, the Medical Director of the Refugee Clinic at Denver Health Medical Center, attended the meeting to seek the Committee's input on how old a baby could be and still get benefit from a newborn screening test. This would apply to only about eight babies statewide. The Committee had discussed the matter at length in March, but did not reach a consensus at that meeting. The Committee continued that discussion at this meeting, with respect to the sensitivity and specificity of newborn screening for certain conditions after the first few weeks of life. Any abnormal results in this population would have the baby's age available, to assist in interpreting the results. The Committee agreed that a 12-month cut-off would be appropriate. The Committee cannot act independently, but can only advise the Department. The Committee's recommendation will be put in writing and sent to the Department's Executive Director.

V. Update: Newborn Screening for Critical Congenital Heart Disease (CCHD)

Margaret Ruttenber, the Director of the state birth defects registry, the program that administers CCHD screening, demonstrated how CCHD data collection is accomplished through coordination between the birth certificate and the birth defects registry.

VI. Public Comment

No public comment was made.

The meeting was adjourned.

The next meeting of the Colorado Newborn Screening Committee will be held on Tuesday, <u>October 18th</u> , 4:00 to 6:00 PM. There is usually a meeting in September. The meeting was moved to this date in order to get our usual meeting room. (Please note that this is the third Tuesday of the month rather than the fourth Tuesday.)
